

## Part I

### A Gentle Death

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**M**y mother has been on my mind. She's been gone now for ten years. Death finally came to her after several merciless years of progressive suffering and pain in the nursing home she had selected to take care of her. We had all discussed end-of-life issues with Mother; we knew this was exactly the quality of life she hoped to avoid.

She had a Living Will, as does everyone in our family. She could trust my brother, as her durable power of attorney for health care. He would do his best to see that her written instructions were followed should she become incapacitated. She had no idea that 65% of physicians surveyed said they wouldn't necessarily follow a Living Will. As it turned out, that simply was not what she needed, anyway.

Mother was conscious and capable of making her own decisions right up to the miserable end. She saw no way out. Pain medication clouded her mind and reminded her that this was not what she called living. The last few months of her life were a nightmare. Nothing she knew about could help her avoid that, living where she did.

Options do exist, each offering its own difficult choices: Hospice, Palliative Care programs, Death with Dignity possibilities, for instance. What's good about them all is that those choices can be the patient's. Or we believe they can.

Surveys show that 80% of Americans want to die at home. I'm one of those – let me go on my own terms: a peaceful end, nodding off in my comfy bed with

my husband holding my hand as he wishes for Shakespeare's flights of angels to sing me to my rest.

#### Likely? Well ...

Death can be far more difficult than we might imagine. So much about death cannot be accurately predicted, even when we hope we have it all arranged. Our bodies may not respond as we hoped. Just when we think the process is under control, something else unexpected can emerge, often causing even more extreme suffering.

Understanding how to deal with issues of the dying often requires help from trained professionals. It's difficult for patients and their families to know how to approach the situation; many are reluctant even to want to. Helping to develop plans for that final exit may seem totally out of the question. Beyond that, saying goodbye to a loved one becomes unthinkable for some, too painful to imagine. Meaningful discussions with our physicians and counselors can guide us to a reasonable approach to managing the sort of outcome we desire.

Examining alternatives is a good way to start. In fact, it might make all the difference. Reports show that while in 1989 only 15% of those over 65 in the general population died in their homes, by 2007 that figure had risen to 24%. A good increase. However, much higher percentages (77 to 97%) of at-home deaths exist for those enrolled in certain end-of-life programs. So learn facts, inspect details. Uncover possibilities, ask

**End-of-life issues are difficult to think about and consequently avoided. Avoidance results in last-minute decisions that are based on incomplete facts and misconceptions. This is the first in a periodic series about this important topic.**

## A Gentle Death

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questions. If one option sounds appealing, consider that one. If another does not, then do not choose that one; move on, keep looking. Here are some choices:

### Death with Dignity

The Oregon Death with Dignity Act is one option. Although voters in the state of Washington passed a nearly identical law in 2008, and in 2009 the Montana Supreme Court approved progress made in such a law in that state, the Oregon Death with Dignity program provides information from 15 years of its successful operation. Other states have Death with Dignity Acts in various stages of development. Since 1997, adult Oregon residents (there is no minimum residency requirement) who are able to make and communicate health care decisions and have been diagnosed with a terminal illness that will lead to death within six months may enter a program to request medication helping them end their own lives in a “humane and dignified manner.”

Of course, it’s not that easy. Safeguards abound. Every part of the program is strictly regulated. A patient wanting the lethal doses must first register: sign and date an application form that is also witnessed by at least two others, one of whom is not a relative, not someone who would profit by the patient’s death, not the patient’s attending physician and not

anyone connected to the patient’s health care facility, if there is one. These witnesses must swear the patient is capable and is making the request voluntarily, without being forced.

This is a tightly-run ship. Nobody merely trots in and is given a handful of pills. A prescribing physician and a consulting physician must confirm the patient’s diagnosis, his prognosis and his capability. A psychiatrist or psychologist must examine any patient whose judgment seems impaired. Many sorts of examinations and determinations are required. All of this happens before the patient is accepted into the program. The law must be followed – and it is a stringent law.

### Check Out These Facts:

- ◆ Only terminally ill patients can register for the Oregon Death with Dignity option. Statistics from this program’s records show that of the 77 deaths in 2012, 67.5% were 65 or more years old, 97.4% were white, 42.95% had at least a bachelor’s degree and 75.3% had cancer.
- ◆ The patient is totally in charge of taking the lethal medication and is never required to do so. Many do not ever take the pills. They merely want them on hand for peace of mind, a measure of security, in case the day comes when the disease becomes intolerable.
- ◆ Between 1997 and 2013, prescriptions for lethal medications under this law were written for 1,050 patients, and 673 of them died from taking those meds. During 2012, 67 died from ingesting the medications, which were prescribed for 115 patients.
- ◆ Other viable options to the Death with Dignity program must be explained by the prescribing physician to the patient before his choice is made.

Live for today ...



But plan for tomorrow.

**Nancy Baldwin Carter**, a Nebraska native, contracted polio in 1948 at age 11. With BA and MEd Psych degrees, she began her career as a high school English teacher and moved on to administering adult education programs in Missouri and Kentucky. Carter founded Nebraska Polio Survivors Association in 1984 and was its initial director.

She was a contributing author to Dr. Lauro S. Halstead’s *Managing Polio: A Guide to Living Well with Post-Polio Syndrome* in 1998 as well as its second edition in 2006. Carter has written three series of columns for Post-Polio Health International – “Leadership,” “Polio Survivors Ask ...,” and “Post-Polio Thoughts.”

## Promoting Positive Solutions

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If none of the above appeals to you, how about laughter? Laughter yoga, where groups of people gather and laugh for an hour (really!), is an up and coming stress reduction technique. Watching funny movies or television shows, listening to comedy or reading humorous books is a stress reduction technique most people enjoy.

I would be remiss if I didn't point out that if your stress levels are extremely high and you are having difficulty managing them on your own, you might want to see a mental health professional for a consultation. In addition to talking about the issues that may be causing your stress, he or she can help you learn effective stress management techniques. ■

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- ◆ Actions taken under this law are not, in any way, legally considered to be suicide.
- ◆ Participating in this program has no effect upon a patient's insurance policy (life, health, accident or annuity).
- ◆ Extensive thorough records are kept on every patient's involvement in an Oregon Death with Dignity Act program and are available to the public.

Deciding on a preferable end-of-life plan can be challenging. Some patients "partner" with other programs as they seek comfort and care in their final months. Not surprisingly, records show that well over 90% of individuals in the Oregon Death with Dignity Act program were enrolled in hospice when they received their lethal prescription or when death came. Many seem to believe that this combination of options lies closest to providing relief from worry about losing their quality of life and dignity as they move nearer to the end. And most choose to meet death in the quiet comfort of their own homes. ■

## PHI Elects Two New Board Members

Post-Polio Health International welcomes two new directors who were elected at a recent board meeting: Sandra Loyer of Ann Arbor, Michigan, and Mohammed Yousuf of Fairfax, Virginia.

In addition to teaching, Loyer has more than 30 years' experience in social work in a variety of fields from neurosurgery to spinal cord injury to primary care. Currently she is in private practice and is a military family life consultant to the U.S. Department of Defense. Her community and volunteer activities include board president of the Samaritan Counseling Center and member of the board of the Ann Arbor Center for Independent Living. She holds an AB degree from Ohio University and an MSW degree from the University of Michigan.



Sandra Loyer

"I bring to the board a lot of experience working with people who have had polio and all the knowledge I have learned from them. I have years of experience working with families and have developed an understanding of their needs and ways to help them meet those needs. Over the years, I have listened very carefully to my patients and clients and try hard to understand their particular situation, culture and belief system. I do not believe in a 'one size fits all' approach. My military experiences have expanded my horizons in understanding the human condition. I look forward to both learning from my participation in the PHI board and to actively contributing."

Yousuf is an engineer and disability rights activist whose previous positions include product design and project engineering for Chrysler Corporation and General Motors. Currently he is a research engineer for the U.S. Department of Transportation. He is founder and president of the Equally Able Foundation and co-chair of the ADAMS Accessibility Committee which works to improve inclusion and disability awareness. He holds BS degrees in Electronics & Communication Engineering from Osmania University in India and an MS degree in Computer Engineering from Wayne State University in Michigan.



Mohammed Yousuf

"As a person who has lived with polio most of his life, I know how important PHI could be to those who have been on this journey. I believe that PHI is the only organization that is still working to enhance the lives and independence of polio survivors, and that means a lot to me. Those of us who have lived through difficult times know what independence means, what mobility means. Through PHI, we can make a difference in the lives of people who have had polio and people with disabilities. I hope to make a difference by bringing to the board my personal experiences of dealing with disability, running a disability organization and working in research areas that touch both people with and without disabilities." ■